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Going for GOLD! Greater Manchester Growing Older with Learning Disabilities: An inclusive research project to reduce social isolation amongst older adults with learning disabilities

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Leibniz-Institut
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Manchester Metropolitan University

Going for GOLD!

Greater Manchester Growing Older with Learning Disabilities:

An inclusive research project to reduce social isolation amongst older adults with learning disabilities

The Greater Manchester Growing Older with Learning Disabilities (GM GOLD) team:

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March 2020

ambition for ageing

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Ambition for Ageing is part of Ageing Better, a programme set up by The National Lottery Community Fund, the largest funder of community activity in the UK. Ageing Better aims to develop creative ways for people aged over 50 to be actively involved in their local communities, helping to combat social isolation and loneliness. It is one of five major programmes set up by The National Lottery Community Fund to test and learn from new approaches to designing services which aim to make people's lives healthier and happier.

The Greater Manchester Growing Older with Learning Disabilities (GM GOLD) team

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Summary

Introduction

People with learning disabilities are living longer and most now live in community settings. However, they are at increased risk of social isolation, with older adults with learning disabilities at particular risk. The Greater Manchester Growing Older with Learning Disabilities (GM GOLD) project aimed to reduce social isolation amongst older adults (aged 50+) with learning disabilities and find out what made somewhere an age-friendly place to live for older adults with learning disabilities. We wanted to find out what older people with learning disabilities think about their local area, whether they feel part of their local community and what supports or barriers exist to meaningful social contacts, interactions and activities.

This was an inclusive research project carried out by a team of 16 older people with learning disabilities (co-researchers) supported by 'research buddies'. The team took part in workshops to get to know each other, learn about different research methods, and develop their confidence and speaking up skills.

Methods

The GM GOLD team conducted interviews and focus groups with 59 older people (aged 50-79 years) with learning disabilities from eight Greater Manchester areas (Bolton, Bury, Manchester, Oldham, Rochdale, Salford, Tameside, Wigan).

Key findings

Age-friendly neighbourhoods for older people with learning disabilities

Important influences on what made an area a good place for older people with learning disabilities to live were local amenities, the environment, transport links, local people and whether people felt safe where they lived. Experiences of harassment, bullying, name-calling and hate crime were common and influenced whether people felt safe going out.

Social contacts, loneliness and social isolation

Many people had not heard of or did not understand the word 'isolation' and were more likely to speak about or use the term 'loneliness'. 69% felt lonely now or in the past. Potential causes of social isolation were not being with, or feeling rejected by, family and friends, loss and bereavement. Feelings of isolation and loneliness could be heightened at particular times of day or year.

Whilst many participants had regular contact with family and friends, others had limited or no contact. Often contact with friends was in segregated settings such as day centres, self-advocacy groups, and groups and activities organised for people with learning disabilities, rather than the local community or older people. These could be important places to see friends; however, it could be difficult to meet new people and many groups had experienced cuts in funding.

Only a few people were in intimate relationships and it was rare that people were married, or living with someone, although many participants clearly wanted to be

Barriers to keeping in contact with people were difficulties using telephones and digital technology, and people being busy. Some people felt that others did not want to see them because of their health or disability, or did not have the confidence or social skills get to know people. Often people lacked support to maintain contact with friends when they left school or moved home. Things that made it easier to see or keep in touch with family and friends were if they lived nearby, social media sites and having support to arrange to see people.

Participants used a range of strategies to manage social isolation and loneliness, such as talking to someone about how they were feeling, keeping busy, going out, using phones and social media, moving home and sharing with other people

Social activities

There were many examples of people living busy, active lives and doing a range of activities that they enjoyed. These included leisure activities, socialising, going on holiday and paid and unpaid work. Churches, religion and spirituality were an important source of comfort, social contact and social activities for some people.

Barriers to taking part in social activities included availability of support, cuts to services and community groups, age, deteriorating health and mobility. Difficulties with memory, spatial awareness, learning and understanding could lead to problems with organisational skills, reading and counting, and have practical implications when travelling or taking part in social activities. People could also find it hard to understand, learn and remember social rules and skills

Growing older: feelings, experiences and beliefs

Most participants viewed growing older negatively and as a time of loss. Growing older was seen as preventing people doing things that they enjoy. Health and mobility could deteriorate, there were physical changes, such as hair going grey or getting thinner, the menopause, and people were concerned about their own mortality and death.

Deaths of people, particularly parents, had a great impact on people emotionally and practically. It was important that people were supported to talk about their feelings, grieve and remember people who had died. Frequently, people had lived with their parents for all, or most of their lives, and had to move home when parents died. This was a time of uncertainty and there seemed to be little planning for the future.

Other people were more philosophical and positive about growing older. People could gain rewarding new roles within their family, and continued to make a contribution through unpaid and voluntary work and helping out within families and communities.

Sharing of findings

The team is reaching key audiences to share their findings and recommendations in a variety of ways, including an easy read report, a film, a workshop for people with learning disabilities, presentations, attending meetings and events, and teaching health and social care students.

Introduction

This report describes how we carried out the Greater Manchester Growing Older with Learning Disabilities (GM GOLD) research project and our findings about how to reduce social isolation amongst older adults (aged 50+) living in Greater Manchester. GM GOLD is part of the 5 year *Ambition for Ageing* programme led by the Greater Manchester Centre for Voluntary Organisation (GMCVO) and funded by the National Lottery Community Fund's *Ageing Better* programme. *Ambition for Ageing* aims to create more age friendly places, reduce social isolation and empower older people in Greater Manchester[1] to live fulfilling lives as they age.

In 2018, GMCVO commissioned Manchester Metropolitan University to lead a Greater Manchester level scaled programme of work, GM GOLD, to support people with learning disabilities aged over 50 to engage in research on how to reduce social isolation and increase belonging amongst older people with learning disabilities. Project partners were Pathways Associates, Manchester People First and SPICE (Future Directions CIC).

Social isolation is an objective measure of how many people someone has in their social network, the quantity of their social relationships. Loneliness is the subjective experience of how people feel about their social situation and the quality of their social relationships (Owens & Sirois, 2019). Social isolation and loneliness are closely linked; having regular social contacts and relationships can increase feelings of social inclusion, belongingness, quality of life and reduce feelings of loneliness (Friedman & Rizzolo, 2018; Fulford & Cobigo, 2018; Lehmann et al., 2013).

GMCVO wanted the programme to create opportunities for inclusive and co-produced research for this marginalised group, enabling people with learning disabilities to have a louder voice in discussions about ageing. There is a long tradition of inclusive research in which 'people with learning disabilities are active participants, not only as subjects but also as initiators, doers, writers and disseminators of research' (Walmsley & Johnson, 2003, p9). There are several examples of research teams made up of people with learning disabilities carrying out research projects (for example, the Wigan Better Together Stronger Together research team, the Carlisle People First research team, the Looking into Abuse Research Team). Advocates of inclusive research believe that this approach will increase acceptability and trust for research participants and ensure that research questions and findings are grounded in and reflect participants' experience.

[1] Trafford and Stockport were excluded as these Local Authorities did not meet the National Lottery Community Fund's participation criteria. However, the Ambition for Ageing programme seeks to ensure that all the learning generated is shared across these areas.

GM GOLD builds on this tradition of inclusive research, as a team of older people with learning disabilities (co-researchers) were supported to plan and carry out the project. The co-researchers were supported by 'research buddies' who had experience of conducting research and evaluations and/or working alongside people with learning disabilities. An expert by experience (DAD) was involved from the very beginning of the project, informing the development of the funding application and project design, and was a research buddy.

People with learning disabilities are living longer and most now live in community settings (Emerson & Hatton, 2008). Evidence tells us that people with learning disabilities are at higher risk of social isolation and face barriers in engaging in mainstream activities (Abbott & Mcconkey, 2006; Myers, Ager, Kerr, & Myles, 1998). Whilst people with learning disabilities can have positive experiences in their local neighbourhoods, many feel that they do not belong, feel different or unsafe (Abbott & Mcconkey, 2006; Hall, 2005; Overmars-Marx, Thomése, & Meininger, 2019; Van Alphen, Dijker, Van Den Borne, & Curfs, 2009). An earlier programme set up by the Foundation for People with Learning Disabilities (1998-2002), named Growing Older with Learning Disabilities, identified social inclusion as a major issue for older people with learning disabilities. The programme found that they often experienced boredom and isolation, finding it difficult to maintain contact with friends, make new friends and get out and about (The Foundation for People with Learning Disabilities, 2003).

In light of the high risk of social isolation amongst older people with learning disabilities, and to ensure that their views and experiences were captured within the *Ambition for Ageing* programme, GMCVO commissioned this piece of research.

Aims and objectives

The overall aim of GM GOLD was to reduce social isolation amongst older adults (aged 50 +) with learning disabilities living in Greater Manchester[2].

Specific objectives were:

1. To create opportunities for inclusive and co-produced research for older people with learning disabilities (aged over 50), supporting them to have a stronger voice in discussions about ageing.
2. To explore what makes an age-friendly neighbourhood for older people with learning disabilities (i.e. a good place to grow older).
3. To explore older people with learning disabilities' social contacts and investigate causes of social isolation
4. To explore social activities that older people with learning disabilities are taking part in and investigate barriers to engaging in activities that they enjoy.
5. To identify solutions to help reduce social isolation amongst older people with learning disabilities and help connect them to wider society.

[2] Excluding Trafford and Stockport for reasons outlined above.

6. To launch and market the learning from the research to ensure Greater Manchester is more inclusive and accepting of people ageing with learning disabilities.

Values and approach

Our research took an assets-based approach which uses 'a community's own assets to achieve positive change using their own knowledge, skills and lived experience of the issues they encounter in their own lives' (Ambition for Ageing, 2018). In addition, we were guided by the social model of disability which locates the construction of disability within physical and social barriers, rather than within individuals (Barnes, 2012; Oliver, 1981).

Project Phases

The GM GOLD project was funded from June 2018 – 31st March 2020[3]. There were seven phases to the project:

- Awareness raising about the project and recruitment of co-researchers
- Learning together and team-building
- Planning our methods
- Fieldwork and data collection
- Data analysis
- Sharing of findings, including a Greater Manchester promotional campaign.
- An evaluation of the impact on the co-researchers.

Phase 1: Awareness-raising and identifying research team members

In the first few months we focussed on raising awareness about the research across Greater Manchester and finding older people with learning disabilities to form a research team. We designed an information leaflet and a leaflet to recruit co-researchers, and set up a project webpage (https://www.ambitionforageing.org.uk/wearegmgold), Facebook and twitter accounts (@wearegmgold).

We shared information about the project through social media, meetings, conferences, events, self-advocacy groups, family groups, Greater Manchester Confirm and Challenge meetings[4], Learning Disability Partnership Boards, service providers and commissioners. We held an information session in October 2018 for people interested in finding out more about the project and being a co-researcher. Often people who were interested felt unable to take up the co-researcher role due

[3] Some of the outputs and sharing of findings will occur beyond the original time-frame due to the impact of the COVID-19 coronavirus outbreak.
[4] Confirm and Challenge meetings are open to people with learning disabilities and/or autism, their families, friends and allies. These meetings discuss, challenge and confirm local Transforming Care plans with those responsible for developing and implementing them locally.

to health concerns (for example, epilepsy), the travel involved, parental concerns or caring responsibilities.

The GM GOLD team

We identified 18 older people with learning disabilities to be co-researchers on the GM GOLD team. Two people stopped coming during the training sessions; one due to health and mobility issues, the other person did not give us a reason. Two people found it difficult to attend some of the later meetings due to life events and health issues; however, they were keen to continue to be involved so remain team members. All Greater Manchester areas included in *Ambition for Ageing* programme were represented.

The team also included seven research buddies from the partner organisations. The facilitator and a younger member of a self-advocacy group acted as volunteer research buddies for two team members, and one team member was regularly supported to attend by a provider organisation. A sibling supported a pair of team members to take part by driving them to meetings and attending the initial workshops with them.

Phase 2: Learning together and team-building

The research buddies planned and facilitated six workshops in November and December 2018. The workshops covered:

- Background to the project
- Inclusive research
- Different data collection methods (e.g. focus groups, questionnaires, interviews, creative methods)
- Ethical issues such as consent and confidentiality.

We also began to plan our research questions and methods.

Workshop activities were interactive and engaging and learning was experiential. This was important to keep people engaged and as people had different levels of understanding. The co-researchers were unpaid volunteers so it was important that they enjoyed the workshops and felt valued. There were prizes for some of the activities and everyone received a certificate and a Christmas gift at the final workshop. There was time to socialise before workshops during morning refreshments and at lunch.

The workshops included team-building activities so that people could get to know each other and to develop trust within the team. Activities also aimed to increase team members' confidence and necessary skills to carry out the research (e.g. speaking up, asking questions and listening). The team set their own ground rules. Workshop presentations used plain language and Photosymbols images to illustrate

the main points. Team members received folders, copies of presentations and other information. We had golden wooden spoons that people could pick up if they wanted to speak. The workshops also gave research buddies the opportunity to gauge the levels of support that might be needed during fieldwork. Figure 1 provides examples of activities and experiential learning in the workshops.

We also talked about how to take care of ourselves. This was important as the research might involve hearing about distressing topics or remind people of unpleasant experiences in their own lives. We explored comfort zones and introduced mindfulness-based techniques to help reduce stress levels if the co-researchers felt that they were moving out of their comfort zone (Kabat-Zinn, 1990). These included breathing techniques and glitter jars to help people settle their thoughts.

Figure 1: Examples of interactive activities and experiential learning

Workshop 1: '1 minute masterpiece'. People got into pairs and took it in turns to draw the person in front of them in one minute without looking at the paper while they are drawing each other. Each pair then introduced each other and showed their portraits. This helped people to get to know each other and practice speaking up.
Workshop 2: 'Going for Gold' quiz. The quiz asked questions about the project with multiple-choice answers. This helped to give information about the project in a fun and interactive way.
Workshop 3: The research team took part in a focus group carried out as part of the evaluation of the impact of taking part (Phase 6). In this way, the co-researchers gained experience of what it was like to take part in a focus group and the information sheets and consent forms used in research projects.
Workshop 4: 'What makes a good researcher?' activity. A volunteer lay on paper on the floor so their outline could be drawn. Then the team discussed what made a good researcher and wrote or drew representations of these qualities on the outline (e.g. listening, keeping things confidential, friendly, treating people with care and respect, non-judgemental).
Workshop 5: the research team completed the Ambition for Ageing evaluation questionnaires. We talked about what we thought about the questionnaires and wrote down our feedback to send to GMCVO. We also looked at some easy read questionnaires developed for other Ageing Better projects.
Workshop 6: 'What am I?' activity. People had a picture of a food type stuck to their foreheads without knowing what the picture was. They then took it in turns to ask other people questions to work out what type of food they were. This helped people to gain experience and confidence in speaking up and asking questions, and to learn about taking turns and listening to other people.

An important guiding principle underlying the workshops was that we were learning together and from each other, rather than non-disabled 'experts' imparting information and knowledge. All of the team members with learning disabilities were experts by experience, having gained expert knowledge and opinions from their own lives and the experiences of other people with learning disabilities.

Phase 3: Planning together

From January 2019 – March 2020 we had monthly GM GOLD team meetings to:

- Continue to plan how to do the research
- Design our interview schedule
- Practice interviewing each other
- Analyse our data
- Decide how to tell people what we found out.

We drew on the knowledge and skills gained from the co-researchers' own life experience to help to plan, carry out and analyse the research. Again, meetings were interactive and experiential. Easy read minutes recorded meeting content and actions.

Phase 4: Fieldwork and data collection

This phase ran alongside regular team meetings. The research buddies supported the co-researchers by liaising with groups and organisations to identify and contact participants, organising fieldwork practicalities (e.g. times, venues, travel), ensuring that the research procedures were followed.

Methodology

We used qualitative methods as we wanted to ensure that the research looked at the meanings older people with learning disabilities gave to their everyday lives, rather than the meanings attributed to their lives by other people (e.g. families and service providers). Many team members had prior experience of interviewing people or being interviewed themselves; therefore, we decided to use interviews as the main method to collect information. We also decided to offer potential participants the choice of taking part in a focus group or an individual interview as the co-researchers felt that many people with learning disabilities would feel safer and more comfortable in a group setting.

Recruitment of participants

We aimed to recruit 50-75 older people with learning disabilities from the eight Greater Manchester areas included in *Ambition for Ageing* (Bolton, Bury, Manchester, Oldham, Rochdale, Salford, Tameside, Wigan). We also aimed for a mix of participants in terms of age (over 50), level and/or type of disability, gender, ethnicity, sexuality, living situation and rural/urban location of home.

Potential participants were identified through the extensive networks of the co-researchers and project partners, including self-advocacy groups, family support groups, learning disability services, older people's services, commissioners and provider organisations. A number of people had also expressed an interest in taking part during the initial awareness-raising phase of the project.

The inclusion criteria for the project were that participants:

- Self-identified as having learning disabilities
- Were aged 50 years or over
- Lived in Greater Manchester (excluding Stockport and Trafford as specified by the funders)
- Wished to take part

Inclusion criteria also included consideration of consent under the Mental Capacity Act conditions; that is, participants could understand, retain and use information relevant to deciding whether to take part in the research, and communicate this decision (by any means) (Department of Health, 2005). If we considered, or were concerned, that someone did not have capacity to consent to take part (for example, people with profound and complex needs or dementia) we would have identified a consultee (Department of Health, 2008); however, this did not prove necessary.

The co-researchers were offered the opportunity to be interviewed. This provided a chance to develop their interviewing skills, to experience taking part in an interview,

to tell their story and to be heard. It can be important that people have the opportunity to tell their own story so that they can then listen to other people's stories. We felt that interviewing each other would help the co-researchers to explore how their experiences and opinions may reflect or differ from other participants, and therefore support reflexive analysis of the fieldwork data. This also gave the research buddies the opportunity to identify how best to support co-researchers to carry out interviews.

Ethical considerations

We obtained approval from the Health, Psychology and Social Care Ethics Committee Manchester Metropolitan University (Ref: 5730). Separate ethical approval was gained for the evaluation (Ref: 2088).

Consistent with the Mental Capacity Act (2005), we did not assume that people with learning disabilities would lack capacity to provide informed consent to take part in our research, and provided as much information as possible in different formats to support them to make a meaningful decision about taking part. Co-researchers and research buddies visited individuals and groups to explain the study in more detail and answer questions. Information about the study was presented verbally, in written format and using a presentation which broke the information down into small pieces. We developed easy-read information sheets and consent forms. These approaches are recommended as the most appropriate to use for people with limited understanding of spoken or written language (Jayes & Palmer, 2016).

Data collection: Interviews and Focus groups

We gathered our data through interviews and focus groups to enable the capture of rich data (Gill, Stewart, Treasure, & Chadwick, 2008). The team designed a semi-structured interview guide with questions about:

- The local area and people where participants lived
- How people travelled about
- Feelings about growing older
- Isolation and loneliness
- Contact with family and friends
- Social activities
- Demographic information

The guide was in plain English with Photosymbols to help co-researchers to remember and ask the questions. Potential responses were included in case a participant struggled to understand or answer a question. There was space to record responses and some of the questions had response options to mark. Questionnaires and other fieldwork materials were printed on yellow paper as many of co-researchers found this easier to read from.

The majority of interviews were carried out by one of the co-researchers, supported by a research buddy. Sometimes two co-researchers took it in turns to ask interview questions, supported by a research buddy. One interview was carried out by a research buddy without a co-researcher at the participant's request. The buddy's role

was to support the co-researcher to ask the questions and follow-up questions. Buddies also took responsibility for arranging interviews, ensuring that information about the project was given and consent obtained, recording interviews, by turning on the recorder and writing brief notes on the interview guide.

Research buddies took the lead facilitating focus groups as these involved experience facilitating complex group interactions and there was more flexibility over content and format depending on who was in the group. The co-researchers supported the focus groups, for example by asking follow-up questions, by explaining some of the background to what participants were saying, and sometimes by taking part.

We asked participants to draw the local area where they lived and to take it in turns to talk about their picture. We asked questions about the places and people in their pictures, for example, what the people are like, what is good about the area, how people travel around. Participants were then asked to write or draw two interests or activities that they enjoy on post-it notes and to talk about where they do these and who helps them to do them. They were asked to think about something that they would like to do and how they could achieve this. Focus groups were also audio recorded and participants completed an 'About Me' questionnaire to provide demographic information.

Phase 5: Analysis

Information from the interview guides and 'About Me' questionnaires was entered onto a Qualtrics database. Focus groups and selected interviews were transcribed. We did not have the resources to transcribe all interviews and field notes captured important issues. Qualitative data from interviews and focus groups was analysed using thematic analysis, a method for identifying, analysing and reporting patterns (themes) within data (Braun & Clarke, 2006). Thematic analysis involves six phases: (1) familiarisation with the data, (2) generating initial codes, (3) searching for themes, (4) reviewing themes, (5) defining and naming themes and (6) final analysis and write-up.

We made the process of analysis accessible to the co-researchers in a number of ways. Quotes from interview notes and transcripts were printed in large font and Photosymbols pictures that reflected the content of the quotes were selected. At team meetings, co-researchers divided into groups to look at specific topics. Each group read aloud quotes, then identified codes and themes by thinking about what the person was saying and if any pictures matched the quotes. The groups arranged the quotes and pictures into different themes and recorded any discussion points on to flip chart paper. People could draw or write words on post-it notes and the flip chart paper.

We also explored the use of personas, fictitious characters loosely based on research participants. The aims of creating personas are:

(i) To help bring together what everyone has been telling us.

(ii) To help describe common situations and challenges that older people with learning disabilities may experience which impact on social isolation.
(iii) To help explore potential solutions.

This method builds on the use of personas in the Being Warm Being Happy inclusive research project (The BWBH team, 2019).

Phase 6: Promotional campaign

Our promotional campaign aimed to reach key audiences across Greater Manchester: people with learning disabilities, families, self-advocacy groups, service providers and commissioners, policy-makers, older people's networks, services, groups and organisations, and local communities.

We identified the main research messages and considered ways to reach different audiences during team meetings. Again, we used interactive activities to identify key messages, such as writing headlines and newspaper stories. We drew on the experience of the co-researchers, many of whom are committee or advisory group members, have experience of working with service providers and commissioners, presenting, writing papers, campaigning and making films.

Phase 7: Evaluation

We wanted to explore the impact of taking part in the research on the co-researchers.

a) Evaluation of the co-researchers' experiences of taking part in the GM GOLD project

We wanted to find out how the co-researchers experienced being part of the GM GOLD project. The co-researchers took part in a focus group during one of the initial team meetings where they discussed their aspirations and expectations for the project. In January 2020, they took part in a follow up focus group to discuss whether being involved in the project had met their expectations, what they had enjoyed about the project and if they had experienced any drawbacks. A separate report provides further details and the findings from this evaluation (Caton, 2020).

b) Ambition for Ageing questionnaires

Ambition for Ageing asked all participants in the programme to complete questionnaires at up to three different time points to detect and describe changes occurring during the programme. Questionnaires gathered information on demographics, age-friendliness of local neighbourhoods, social contacts and activities, psychological and physical health. The co-researchers were asked to complete these questionnaires. Questionnaire analysis and reporting of findings is being carried out separately by Greater Manchester Combined Authority, and nationally by Ecorys.

Key findings

Participants

We spoke to 59 people across Greater Manchester as shown in Figure 2. The mean age of participants was 58 years (SD = 7.09; range 50-79 years) (4 missing values[5]). Figure 3 provides further demographic information (totals may be lower than 59 where no response was recorded).

Figure 2: Greater Manchester areas where participants lived

	Frequency (N)	Percent (%)
Bolton	6	10.2
Bury	7	11.9
Manchester	11	18.6
Oldham	8	13.6
Rochdale	7	11.9
Salford	6	10.2
Tameside	8	13.6
Wigan	6	10.2
Total	59	100.0

Figure 3: Demographic information

		Frequency (N)	Percent (%)
Gender (2 missing)	Male	35	61
	Female	22	39
Ethnic background (5 missing)	White/White British	52	96
	Black/Black British	2	4
Sexuality (18 missing)	Heterosexual/straight	35	85
	Gay or lesbian	4	10
	Bisexual	2	5
Religion (21 missing)	Christian	32	84
	No religion	6	16
Who live with (2 missing)	On my own (with or without support)	27	47
	Supported living	18	32
	With family	8	14
	With partner/wife/husband	3	5
	Other	1	2
Carer[a] (6 missing)	No	39	74
	Yes	14	26

[5] Missing values show the number of participants for whom no response was recorded. They are excluded when calculating frequencies and percentages.

[a] Responses showed different interpretations of the meaning of the word ‘carer’. Some people understood it to mean having a caring, positive relationship with someone, rather than ‘someone who looks after a family member, partner or friend who needs help because of their illness, frailty, disability, a mental health problem or an addiction and cannot cope without their support’ (NHS England, 2020). At least eight people mentioned caring for family members now or previously. Other people talked about housemates, other people with learning disabilities that they spend time with or pets.

Key themes

The key themes are organised around the project aims and objectives:

1. To explore what makes an age-friendly neighbourhood for older people with learning disabilities.

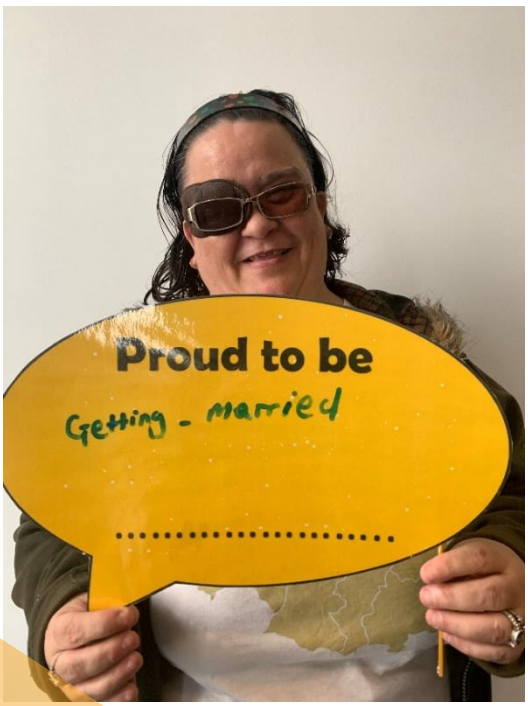
2. a) To explore the social contacts that older people with learning disabilities have.

   b) To investigate barriers to social contacts and potential causes of social isolation

3. a) To explore the social activities that older people with learning disabilities are taking part in.

   b) To investigate the barriers that prevent people with learning disabilities from engaging in activities that they enjoy.

4. To identify solutions that will help to reduce social isolation amongst older people with learning disabilities and help connect them to wider society.



1. What makes an age-friendly neighbourhood for older people with learning disabilities?

Important influences on what made an area a good place for older people with learning disabilities to live, and therefore an age-friendly neighbourhood, were local amenities, the environment, transport links, local people and whether people felt safe where they lived.

Local amenities

It was important that there were things to do and places to go locally, including amenities such as cafes, shops, banks, libraries, and doctors and leisure activities. Local amenities can provide opportunities for social contact and interaction, reducing the risk of someone being socially isolated.

> *Support: "Would you like me to tell [the buddy] because it can be hard. [She] goes to the same café every day and has a brew and a trifle, don't you, and then that's where you meet people isn't it?" (60[6])*

> *There's a [supermarket] near us and there's a market and there's swimming baths there like a sports centre, with swimming baths, Jacuzzi, sauna, tumblers for kids. (62)*

> *"I have a laugh with them. I go to charity shops, get to know the staff there, have a laugh and a joke with them. If they go out the top [of the shop] I can go in there and have a natter to them. That's an everyday thing for me now." (28)*

However, in some areas local amenities such as libraries, banks, shops and cinemas had closed, meaning that people had to travel further distances to access them and might miss out on the social contacts when out and about locally.

> *I don't go to places where I live. Only the [self-advocacy group]. Don't go to any day centres as it shut down. Go to the shops sometimes for a nosey. Get a magazine or a tv mag. Go to the pub near us for a little drink. Just myself and my friend. I like walking around [name of large] Park sometimes – it's near us. There's a library in the town centre but it's too far to go so I go to another one. There isn't a local one anymore. Used to go as had a library card. I went to the leisure centre in the town centre the other day, swimming. There used to be a cinema but there isn't now. I've got a doctor's health check coming up. I've got asthma. I used to catch the bus to Wigan Pier a long time ago. It's shut down now. (4)*

> *Not enough banks to get money out. They've closed, only one shop. (9)*

Whilst participants gave examples of being present in their local communities, many places that people talked about going to were groups or activities organised

[6] Numbers in brackets relate to each participant's identification number. Quotes from transcripts have quotation marks, whilst quotes from notes do not.

especially for people with learning disabilities. It was less common for participants to talk about groups or activities for local people, and they rarely talked about going to groups or activities for older people.

> *I love living my house. Going to drama. At the [theatre]. On a [weekday] evening. I go to a day service. There's like an outreach group. I go three days [during the week]. We go out. Enjoy ourselves. Manchester or Bury or somewhere else. Day trips out. I go to Gateway club on a [weekday] evening. And I work in a charity shop on a [weekday]. And when I move into my new [home] I go to Coronation Street, a tour. That's something I want to do. Going to snooker. Going to bingo. Going to Ascot. As a group. (7)*

> *Participant: "I come here [to the day service] every day. Monday, Tuesday, Wednesday, except for Saturday…"*
> *Buddy: "What do you do on a Sunday?"*
> *Participant: "Come here."*
> *Buddy: "What about the evenings?"*
> *Participant: "Sometimes I watch a bit of telly."*
> *Buddy: "You wouldn't go out?"*
> *Participant: "No. I don't go out often. Sometimes I come here playing pool." (27)*

People

Encounters and interactions with local people had an important impact on whether participants thought that their local area was a good area to live. Friendly local people helped to make somewhere feel like a good place to live. Participants mentioned contact with people who they saw locally; post men and women, shopkeepers, paper deliverers, passerbys, and people when they were out and about.

> *I like the area. People are friendly. It's a nice neighbourhood. Friendly. (4)*

> *Neighbours, shopkeepers, I always talk to people wherever I go, I get to know them. (2)*

> *Next door neighbour, post woman, say 'good morning' to people passing (3)*

Relationships with neighbours could provide positive social interaction, friendship, practical and emotional support. Some people described regular contact and close, supportive relationships with their neighbours.

> *"I just like me own home and my neighbour, great to get on with. When I first moved in I didn't get on with me neighbours but now I get on with me neighbours because I gave them all nicknames. So, yeah, I get on with my neighbours good because I realised they are getting old and pensioners so I'm thinking I've got to cool down and respect me oldies, and that's what I'm doing, respect my neighbours. I've got new neighbours and they're great to get on with. Me partner had an invite for lunch to their house and we went round we had a lunch and a long chatter about each one of us and they talked about their religion and we sat there and listened to them and they made us like part of their family and to me that's good." (28)*

Nice and friendly. My next door neighbour mows my grass. He gives me a cream cake every Tuesday. (7)

"I have good neighbours, when, when I'm on my own they'll check on me, see if there's anything I need or, you know, if I need anything to just go and knock on the door."(59)

However, some people had less positive relationships with neighbours, or described situations where neighbours had become more friendly and accepting over time.

We've got neighbours but they never talk to us. (8)

One neighbour is a devil. Always causing trouble with the carer and I don't like it. (15)

Used to be all elderly people who looked out for each other, weren't used to people with learning disabilities but all friendly. (21)

Many participants talked about experiencing bullying, name-calling, harassment and hate crime by local people. This influenced whether an area was perceived as a good place for people with learning disabilities to grow older. Negative experiences with school-children and young people were often mentioned.

Researcher: What are people like in your area?
Participant: Horrible. They don't like people with a disability. Call names (11)

I don't like being bullied. A few years I went to the museum and people called me names and I got bullied. I reported it to my dad and my dad reported it to the police and the girls got arrested. (9)

Kids watching on the fence. Call you names. (4)

Occasionally, people did describe positive relationships and enjoying contact with younger people.

"So I seen my neighbour's kids grow up and I taught them to respect the oldies and I did and they respect me because I'm an old person. And if they was being good, not making noise, I treated them at the weekend because they used to play football near my front door, so that's what I done, I treated them. I got them ice lollies. They used to call me Uncle [name]. So I was proud of that. They respect me. And I see the lads growing up, they got married, they've had kids, so I told them to tell the kids to respect you. They listen to me, their kids listen to them." (28)

I live near the motorway. Past the school. It's quiet, you see kids playing outside. My sister works at after school clubs, I like that. Seeing the kids playing outside. (34)

Co-researcher: "Do you think where you live is a good place for older people to live?"

Participant: "Uhm, [slight pause] yeh, uh, you get some young uns in, we've got, we've got a couple of young uns in, and I get on great with um. Uh, like, imagine it's like this now, we go and sit in the garden and have a chat and what have you, and then like, they can come and go whenever they want, you know, if they get fed up, they're sitting out, it's too hot in sun, you should go and sit in your flat for to cool down. Yeh."
Buddy: "So you think if somebody's in their 60s and 70s that they'd still feel comfortable, or do you think it might be a bit much for them?"
Participant: "I think it might be a bit too much for them…but for me, it's, I'm fine where I am, I love it."(48)

Environment

People talked about the quality of the local environment. Important aspects were whether the local area was clean, quiet or noisy.

> *Lots of litter. Schoolchildren are noisy. Shouting by the park. (56)*

> *Too noisy. Kids banging on doors. (20)*

> *Problem with neighbours and kids shouting at night after they've been to the pub (46)*

Having access to green space and opportunities to be outside was also important and people mentioned gardens, local parks and green areas.

> *It's nice. I can go for a walk. To the woods. The canal. We get loads of birds because of the woods. I go to the shops with staff. I will go on the bus to other places. I'm having a few falls at the moment but I used to walk to the green and sit with my partner on the benches there. (21)*

Travel

Being able to travel about is important to meet people and access places and activities. Local transport links were an important influence on whether somewhere was a good place for older people with learning disabilities to live. Accessibility of public transport was important; for example, cost, proximity and ease of use. Many people used public transport and found the free travel pass invaluable. Some people found it hard to read or understand bus timetables or leaflets, because of the font size or as they were too complicated. For some participants, using public transport was an enjoyable activity in itself as well as a means of getting around.

> *Understand the busses. Timetables on busses, they are never on time, make it harder. (28)*

> *I like going on the buses. I'm a bus enthusiast. All the buses – buses to town, to [another town]. I could get the tram but I don't do trams, I like buses. The nice old buses. (62)*

Reliability, availability and frequency of public transport, and proximity to bus stops, train and tram stops were important, as was feeling safe when using public transport.

Bus stops. Not enough. Drunks at the bus stop. Brother drops at bus stops. Bus and tram are easy because they are close. (11)

Bus – two in a blue moon. Or bus, run from the club and walk part way. (18)

Participant A:"Yes, that's why I don't use the tram much cos you do, you get young uns on there and they're like really nasty – "
Participant B:"Yeh."
Participant C: "If you just say to them can you please be a bit quiet they just swear at you. Others agreeing. Get off if you don't like it they say." (58, 59, 61)

Some people found it easy to travel about and could travel independently. Other people relied on staff or family members to help them to travel to places; either supporting them to use public transport, or by driving them to places. No-one we spoke with drove a car, although one person wanted to. Access to a car could be limited when several people living together shared a car, or if staff members could not drive.

Participant: "...want to drive"
Buddy: "What, you'd like to learn to drive?"
Participant: "Have my own car."
Buddy: "So is there anything that's stopping you from doing that?"
Participant: "difficult to say, because I'm autistic and they say you're not allowed to.... tell you you can't do it.. Stops you from doing it." (62)

Go out with dad in the car on a Sunday. The car is in his name. Staff are annoyed that dad has it. (21)

Support worker: She used to go out on her own but now she only goes out with staff. All her staff have cars except one. Gets taxi with that staff member. Very lucky to have staff with cars. She is lucky that her staff drive. (41)

People might need support due to concerns surrounding safety, health and mobility, getting lost, or being able to pay. Sometimes this reflected staff or family concerns about health and safety.

Worried about getting lost and getting off at the wrong stop. (34)

Mum's car with sister driving (to the centre). I don't get the bus. They won't let me on it because of my seizures. They should but they won't. Couldn't go to the centre yesterday because sister had a headache and mum can't drive at the moment. She has her foot in bandage. I can't go out on my own. (19)

Strategies that helped people to travel about included support from family or staff, travelling in groups with friends or people they lived with, knowing the area or place that they were travelling to and support to learn new routes.

Bus pass helps. Need help to pay. Staff on the bus. (55)

Need someone with me to stop me getting lost. Niece gives me a lift. Travelling with other people (e.g. in groups at night) makes it easier. (34)

Not going to places he does not know. If he did go somewhere new he would need support. (53)

Feeling safe

Feeling safe was an important theme. Whether someone feels safe to go out is likely to have a direct impact on whether they are visible in their local community, whether they see other people and take part in social activities, and therefore their risk of social isolation. Whilst many people felt safe going out this could vary, in particular, according to time of day.

Not when it's dark. You think somebody's following you. When I walk to the bus stop at ten thirty, eleven o'clock. I keep turning my head. It gives me the creeps. You don't know who's following you. (33)

In the day I do [feel safe]. I stay in at night. I never go out at night. [What would help me feel safer is] get friends to make sure I'm happy. I have very nice neighbours who check on me and if I need anything I can call them. (9)

"I feel safe during the day because I know I'm at home." (48)

Direct experience of crime and awareness of crime in the local level influenced people's feelings about where they lived and whether they went out.

Used to [feel safe] but not anymore. Gangs at the top of the street. Gangs didn't used to be there. Been attacked 4 years ago. (11)

The area is a bit wonky. Always police looking for people. (15)

"It's a dump area now. All the druggies…..The area's rough… But I'm looking to move. The area isn't a savoury area because a lot of young people are trouble. So most of the time I stay in and that's not healthy staying in all the time. I do go out. To [drop-in], see my friends there. I do training with [name of group]. But the evenings are worse. If I lived somewhere else I would go out, somewhere safer." (62)

Experiences of harassment, bullying, name-calling and hate crime could influence whether people felt safe going out locally or further afield.

I don't feel safe going out. I get called names. It's not safe on the tram with school kids. (8)

Not safe because of children calling me names. I try to get away from them. There was a murder in the area. A pocket alarm [would help me feel safer]. (1)

There were a number of ways that people could feel safer in their local areas, such as personal and home security devices, neighbourhood watch schemes, improved lighting and more visible policing.

Participant: "This is where I live. My house. It's not far from here. It's just off [road name]. It's a nice big house. It's been modernised. It's got camera in it in case we get broken in. It's a normal house just like everybody else's. When we go past it, our car's at the front anyway. It's nice. It's nice inside. It's cosy. It's lovely."
Co-researcher: "Is it a good area?"
Participant: "That's why we've got cameras. It's a good area but sometimes….. It's an urban house but if you go out somebody watches your house for you so if someone breaks in you've got the police there. There's like a watch, they watch you go out they watch you go in so they know where you're going, it's good." (32)

When it's light. Don't feel safe in the dark. I keep my mobile phone on me to keep safe. I have my sister's and carer's number for an emergency. Maybe more lighting. You can fall. I fell over once. (3)

More police [would help me feel safer]. The government cuts means there are no police around. A care worker to go out with. (11)

Other strategies people talked about to help them feel safe were travelling by car or taxi, with other people or in a group. Many people felt safer if there were paid or family carers at home. People also talked about the importance of letting people know where they were going and having a mobile phone and numbers to contact if necessary. Knowing an area well and people who live locally could also help people to feel safe.

I feel safe with staff. Afraid of getting robbed so don't go out on my own. If I had staff all the time or if I had a dog [I'd feel safer] (2)

[I feel safe because] I tell the carer where we're going and she knows when we're going out and will come back. If someone attacks you, you can call the carer. I used to live on my own in another area and had a vicious break-in. I would phone the police [to help me feel safer]. (15)

[I feel safe going out because of] people. People I talk to out and about. (14)

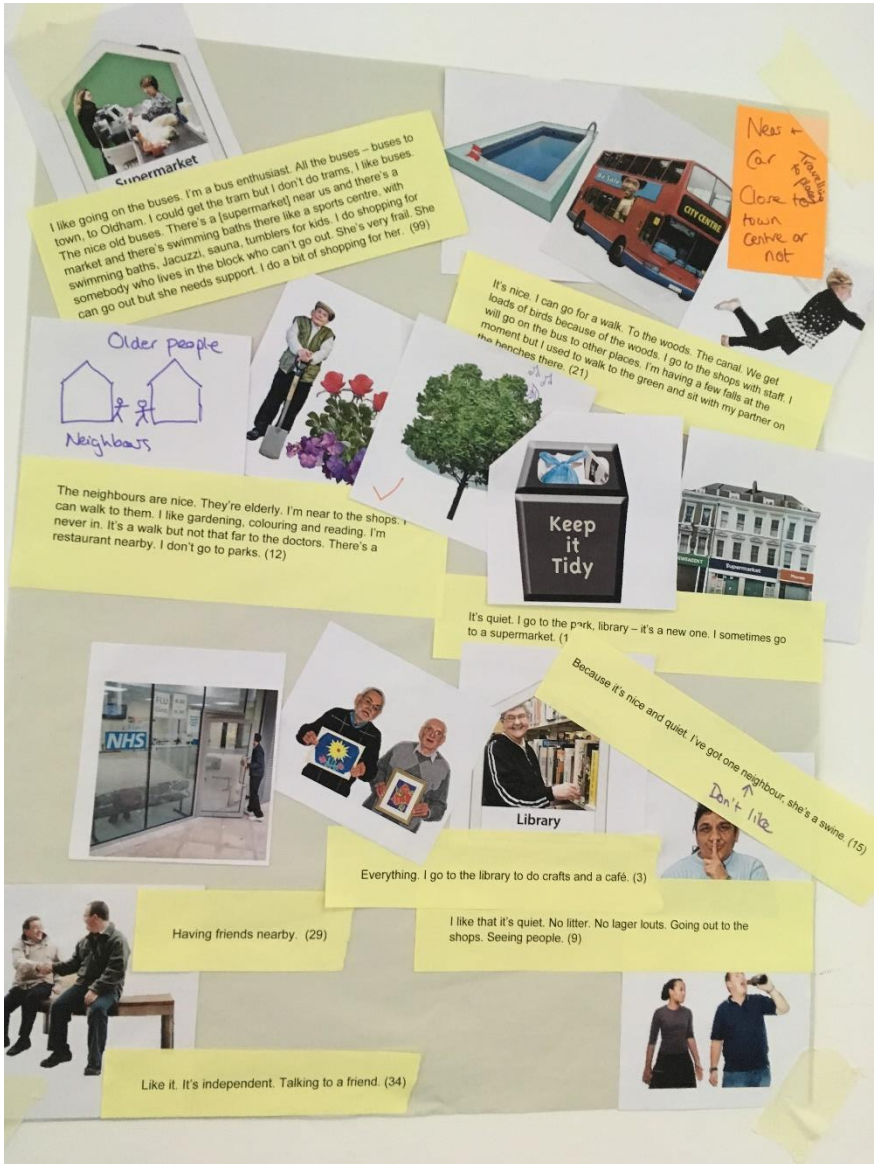
Sense of belonging to place

Two-thirds of our participants told us how long they had lived in the Greater Manchester area where they currently resided. Of these, approximately a third had lived in the area over 10 years, and approximately half had lived there for all their life. This could help people to know the area, and to develop local relationships and have a sense of belonging.

Participant: "My street. Yeah it's ok my street. Like royalty."
Buddy: "Wow. Have you lived there a long time?"
Participant: "Yes. 1970, 1976."
Buddy: "What is it like now compared to when you were younger?"
Participant: "Been on our avenue since 10 or 11. It was a good home."
Buddy: "Is it still a good home?"
Participant: "Excellent, thank you." (59)

"Uhm, I mean I like [the area] because I was brought up in [the area]….Well where I was before that – the paper shop know me anyway, cos I've lived up there nearly 40 years, and uh I got quite friendly with them, and uh, I quite like um." (48)

Length of time living somewhere is only one aspect of a sense of belonging to place. Feeling safe at home and in the community are important indicators of belonging (Strnadová, Johnson, & Walmsley, 2018). Frequent experiences of hate crime from local people may result in people not feeling accepted within a community. Taking part in groups and activities for people with learning disabilities, rather than local communities or older people without learning disabilities, might mean that older people with learning disabilities have more of a sense of belonging to a learning disability community.



Some analysis of what participants thought makes an age-friendly neighbourhood.

2. Social contacts, loneliness and social isolation

Understandings and experiences

We asked participants what they understood by the word 'isolation', whether they have felt lonely now or in the past, and how being lonely made them feel. It was hard for some participants to separate concepts, understandings and experiences of isolation and loneliness. Many people had not heard of or did not understand the word 'isolation.' They were more likely to talk about or use the term 'loneliness'. However, often there was understanding of the concept of 'isolation' as not seeing anyone, not going out, having no-one to talk to or listen to, and being on your own.

> *Not heard of it [isolation]. Heard of loneliness. When no one comes to see you. In here the staff are always here and banging around – it's good. (20)*
>
> *When you don't see anyone for about a month. (13)*
>
> *Means you're lonely, don't have any friends and are fed up. (42)*

Potential causes of social isolation were not being with or feeling rejected by family and friends, loss and bereavement. Feelings of isolation and loneliness could be heightened at particular times of day or year, particularly evenings and night time, anniversaries, and when alone at home.

> *"Isolation? Being locked in your own home, in your own bedroom. Having no meals. Having no friends. Having no one to talk to, just locking yourself away. Having no friends or no one to speak or hear. I know it's hard, I've been there, and that's how it still feels, pause. And having what I've had done to me that still feels like being isolated, stuff….. When I've been at home on me own. When everyone's pushing me away and I feel like I'm not wanted….Also having a family that love you , but don't come down to see you regular because they're always at work. (29)*
>
> *When I lived with my sister - when she was out all the time. Neighbours did not bother with me. (50)*
>
> *The staff are around - get you up in the morning, do breakfast and just leave you. We've got buzzers. I can go on my computer if I need to. (20)*
>
> *At night-time when staff go home she gets quite lonely. Other than the company of staff there's no one in the area who she would see. When staff leave at night she is struggling at the moment as she gets lonely. (41)*

Some people linked the word isolation with their own or other people's experiences in long stay institutions, being locked up or in prison. This may be associated with the risk of older people with learning disabilities having been placed in institutions. Such understandings of isolation may differ from other culturally created words and assumptions, demonstrating the different histories and experiences of many people with learning disabilities compared to other people.

When people kick off they might put you in isolation. Frightened that they might take my belongings. In [the institution] you were put in isolation when you were kicking off. (2)

When I lived in [institution] hospital I couldn't see people I liked. (13)

Of the 35 people who responded to the question about if they had ever felt lonely, 24 (69%) said that they feel lonely now or had done in the past. Feeling lonely or isolated can have negative impacts on emotional wellbeing, and people described feeling sad, miserable, angry, scared, frightened, stressed, confused, distressed or agitated. Loneliness could have a serious detrimental impact on sleep and mental health.

I feel lonely when I get really down and I can't find things. I write things down and I don't know where they've gone. (7)

Support worker: Sad. Sometimes happy. Agitated. Can't really sit down and settle. Can't sit down. Don't know what to do with her. (41)

I kept being poorly. Lived in supported tenancy. Wanted to live on my own so lived in a flat. No communal area. Would see staff for meds and that would be it until tea time. I couldn't sleep. See things in shadows. House of horrors. I went to [the hospital] a lot to see a social worker, so came here. Much better. (22)

Quality and quantity of social contacts

We talked with people about how often they saw family and friends, where they saw people, and what helped or made it difficult to see people. Many participants had regular daily or weekly contact with family and friends; of the 43 people we interviewed only one person said that they did not see family or friends (2%). However, other people had limited or no contact, and often contact with friends was in segregated settings. Approximately a third (32%) of participants lived in supported housing so would be expected to have regular contact with support workers and other people that they live with. Approximately half (48%) lived on their own, but at least half of these had support so should also have regular contact with support workers. 14% still lived with family and 5% with their partner, wife or husband.

Having regular contact with people does not necessarily ensure high quality social interactions or relationships, or stop people from feeling lonely, however. For example, the quality of someone's social contacts may be different with people who are paid to be with them compared with people who they have chosen to be with. People might not have chosen or get on with those who are paid to support them, who they live with, or who they spend time with at activities and groups.

Buddy: "Do you get along with your staff?"
Participant: "No, not always, no. depends who. … but some, some of the – I'm not friends with some, I get bullied most of the week, every week at [the social club]…and I keep telling staff and and they don't – not seem to do anything about it and yet I'm getting upset every week, you know, every week. I'm

getting bullied .... getting bullied. They're acting like children...don't know what to do." (61)

Contact with family

People talked about contact with parents, siblings and their wider family circle (cousins, aunts, nephews and nieces and in-laws). Some people had frequent, regular contact with parents. However, for other people contact with parents was not in person or was less frequent.

> *Visits mum on weekend. Garden together (44)*
>
> *Speak to mum and dad on phone every couple of days. (53)*
>
> *Dad on the phone - rarely see him. Might start going again. (50)*
>
> *Every week speak [to family] on the phone. See them once a year…. Would like to see family more than once a year. (55)*

Those participants whose parents were still alive were aware that they would die and not always be there for them.

> *Of me original family my sister and dad and my sister's friend, my aunty and cousins, if me aunty goes there's only me dad left. There will be a time when me dad, when he won't be here. He's nearly always saying that to me. Me sister's always saying we'll have to sell his house. (20)*

People clearly missed the contact and relationship with parents after they died; this is discussed in more detail in the section about feelings about growing older. Sometimes people had reduced contact with other family members after their parents died.

Participants also talked about contact with siblings and wider family. The frequency and quality of this contact varied. Siblings and their wider family clearly played an important role in some lives, providing company and emotional support, advocating on their behalf and providing practical support to travel, do things and meet people. Visits, telephone calls and face-to-face messaging helped maintain contact with family that lived further away or abroad.

> *Goes to sister's to watch TV…[talks about tv programme in detail]. She lives [nearby]. They go to the airport. One brother lives in [in the South of England]. He comes here to visit. Does a BBQ. Another brother lives [abroad]. They keep in touch, Skype, webcam with pictures…[talks about brother's garden in detail]. He saw his sister [who lives down South] a long time ago. He has nieces [abroad] and speaks to them. (37)*
>
> *Talk to my brother on the phone, he lives in a bungalow on his own, See him Christmas and Easter with staff. (33)*
>
> *"..like I go out sometimes when I go out with my cousin, I go out with her sometimes, and I go in her car and she takes me somewhere to see all the family or something like that." (39)*

I like a lot of things. On different days….. I go to all of them [examples given] with my sister. Everything I do my sister takes me to. (7)

However, family relationships were not always supportive. Family members could get new commitments, which meant that they were less able or willing to spend time with or support someone.

"…I had enough with my family being the same, they were the same with me, yeh. It was always like - always having a go at me….. when I was younger yeh. It was just my parents were causing my crying when I were younger and my brother and sisters and yeh." (61)

See family once in a blue moon, has a sister, some nieces and nephew but don't see them often. Told her sister off a few weeks ago for not visiting. (21)

[My cousin] got married. He spends all his time with his family. (56)

Some people had experienced very limited or no family contact throughout their lifetime, or had lost contact with family, for example, after parents died.

Not seen relatives since I was about 3 or 4 only been to their house a few times. (18)

Don't know family. Don't remember parents. I was so little (22)

I'm looking for my real sister- but she don't want to know me. I want to find niece and nephew. (4)

Contact with friends

Some people spoke about having many friends or having close, long-term friendships.

Don't have family. Have lots of friends. See [friend's name] every month. (35)

Friends. Loads here [at the self-advocacy group]. [Name]- he's alright but makes me late when we have a drink. (34)

[Woman's name] - with a learning disability works at [the supermarket]. I've known her since I was 8 or 9. She comes for tea. (12)

However, often people clearly interacted with few people, and at few places. Many of people we spoke with generally saw friends at day centres, self-advocacy groups and groups and activities organised for people with learning disabilities. Often, these places were an important place to develop friendships and see friends and people would have been completely isolated without them.

I do groups at the day centre. [The self-advocacy] meeting is the only one I go to now. We've all been in a group since it started - if I didn't go I'd get bored around the house. (20)

No-one to talk to in the flat. The only time I talk to people is when I come [to the drop-in] or go to clubs. (17)

However, it could be difficult to meet new people and keep in touch with friends.

> *[I see people] here at [the self-advocacy group]. But I would like to go out and meet more people. [29]*

> *Talk when I see them. Don't see friends I used to - I would like to. (50)*

> *The others, can't tell you when I last saw them. They just move as if I know where to go to. 95 year old. Been friends with him since in a pram. (18)*

It was less common that people talked about meeting friends in other settings, although some people did talk about visiting friends' houses, speaking to people at church, seeing people whilst out and about, or meeting people in the town centre or for a cup of tea or coffee.

People live with

For those people living in supported housing or sheltered accommodation, housemates or other residents also provided social contact. Relationships varied. Sometimes people described positive social interactions, friendships and a sense of community where they lived. However, sometimes, people did not always choose or get on with people they lived with.

> *Participant: "…and if I get fed up I just go in the community room.*
> *Research buddy: "Just meeting friends, chatting."*
> *Participant: "Meeting friends, make a cup of coffee, take my coffee down and go and have a chat with them." (48)*

> *Sometimes I like [my housemate] sometimes I don't….. He shouted at me. (5)*

Intimate relationships

Only a few people were in intimate relationships and it was rare that people were married, or living with someone.

> *Engaged to get married soon, met at [a drop-in centre] after Christmas Eve. See her once a month. (15)*

> *"Me partner helps getting me out of the house." (28)*

> *Participant: "I went to [town] last night with my boyfriend for my dinner. I enjoyed that."*
> *Buddy: "So you've got a boyfriend. How often do you see him?"*
> *Participant: "Saturday. Friday sometimes."*
> *Buddy: "What do you do when you go out?"*
> *Participant: "We go round the shops" (3)*

> *"And seeing my girlfriend too at the clubs and going out with my girlfriend. Going, going to my girlfriend's house, and going out with her to – going to [the cinema] - once a week on Monday…. I see her all the time, I go to her house and I sometime… just say now and again I go to my girlfriend's house or she comes to my flat." (61)*

Other people clearly wanted to be in an intimate relationship but were not. Some people had watched their younger family members grow up and form relationships but were not yet in a relationship themselves. One participant mourned the loss of romantic relationships as she grew older.

> *Get a new girlfriend and get married. My nephew is already married so it's me now I've got to think about. (7)*

> *Participant: "Dream. In bed. Dreaming."*
> *Buddy: "What would be your best dream you could have?"*
> *Participant: "Getting married."*
> *Buddy: "That's a lovely dream. Who do you talk to about that?"*
> *Participant: "Here."*
> *Buddy: "How do you think you could find out about meeting a partner and getting married?"*
> *Participant: "I've waited a long time since I was a young boy. Since I was 8 year old. I've been to lots of weddings. I went to my cousins' weddings. My cousins been married. They all are. [names them]"*
> *Buddy: "You've been to all the family weddings?"*
> *Participant: "Yes. Now I'm waiting for it."*
> *Buddy: "Now, you're waiting for your wedding"*
> *Participant: "Yeah. I'm 51." (26)*

> *I wish I was younger. I wish I was 21 again. I used to see all the blokes after me when I was younger. They mess me about. They want the young ones. I wish I was 21 again. (34)*

Sometimes, family, support workers or services created barriers to relationships and people did not have easy ways of contacting people.

> *I saw my ex-girlfriend's mum and she wouldn't see me again and I don't know when. We used to go swimming together and I miss her. Last time I kept in contact with her sister but I haven't got her number. I've not seen her since swimming. (20)*

> *Carers stopped me seeing my girlfriend, they put down the rules. Doing an assessment to her staying overnight. Stopped us seeing each other. (4)*

> *(My partner) used to live here but became unwell so she moved next door [to another supported house]. (21)*

Maintaining social contacts

Some people had no difficulties seeing people. People kept in touch by meeting up face-to-face often at clubs, groups, drop-ins and day centres. They used telephone, text message or video call. However, participants could need access to or help to use telephones and digital technology, for example, dialling, understanding how technology works, and remembering passwords.

Meeting up, telephone, email but can't remember password. Going to [city] in June/ July to see family. Internet on IPad. I can't do it but my sister does it for me. (7)

Sometimes I ring them. Sometimes message them using my phone but I'm not that good (we did a media course). My friend phones me. (34)

Has a phone but can't dial so [partner] dials for him. (21)

"I don't use a computer, but I wouldn't mind an iPad so I can get in – so I could get in touch with my sister and speak to her on that iPad." (48)

Another barrier to using digital technology were associated risks of losing phones, hackers and theft.

Buddy: "You've drawn a computer, does anyone else have a computer?"
Participant A: "It keeps breaking…. cos of these hackers and so I've given up the computer getting fixed."
Buddy: "Right. What about mobile phones, does anybody have a mobile phone?"
Group responding together, a few saying they have phones. 'I'm always losing them' 'it was always getting stolen'...
Participant B: "Uh, I think when these young, young uns are – who , do nothing but steal, once they see you with a mobile phone they'll ask you, oh can I borrow your phone and then they, then they run off." (Focus group)

Things that made it easier to see or keep in touch with people were living near to friends and family, social media sites and having support to arrange to meet someone; for example, making phone calls and reminding people.

I need someone to write it down, if it's not written down in diary. If I didn't get a phone call last night about here [coming for the research] I wouldn't know. (31)

As discussed elsewhere, feeling safe, transport and health could make it difficult to see or keep in touch with people. Other barriers to keeping in touch with people were people living far away, lack of support, other people being busy, or the person themselves being too busy with organised activities.

Support worker: You don't have a lot of time to go and see people as you are busy with activities. Too busy. (6)

Buddy: Is it easy or hard to see people that you know well?
Participant: It's hard, very hard [to keep in touch], because if I ring my aunty up she's always out at the hospital, ring my niece up she never answers, ring my brother up , he'll answer or he's always at work and then I don't have anyone else after that.
Buddy: So people are busy or don't answer. (29)

Some people felt that other people did not want to see them because of their health or disability. Others commented on how it could be difficult to have the confidence or social skills get to know people.

> *Having epilepsy. Some people don't want to talk to me. (1)*

> *Hard to get to know new people. Getting to know someone and their life story. … No family. No one to stick up for you, help you get out of your shell and talk to new people. (4)*

Coping with social isolation and loneliness

The people we spoke with used a range of strategies to manage social isolation and loneliness. A common strategy was to talk to someone about how they were feeling, for example, staff, family, partner, friends, social worker or a self-advocacy group. Keeping busy, going out to avoid being at home alone, and using phones and social media were ways of combatting loneliness for some people. Moving home and sharing with other people was another potential solution.

> *Last year I bottled something up and it made me feel sick. I talked to someone in the end and I felt better. (12)*

> *Doesn't bother me. TV and DVDs keep me occupied. (9)*

> *Listen for phone if mum goes next door. Or phone, text, Facebook. (19)*

3. Social activities

There were many examples of people living busy, active lives and having fun. People talked about a range of activities that they enjoyed doing at home, locally or further afield, alone or with other people. These included home entertainment (e.g. watching television or films, playing computer games), creative activities, relaxation (e.g. doing yoga, having a bath), watching and playing sports and exercise. People talked about going to pubs, clubs, discos, karaoke, gambling (e.g. dogs and horses, bingo). Many people enjoyed doing housework, cooking and gardening; often these activities were done with someone for support rather than alone. Popular activities included going to shops, markets and car boot sales.

> *City supporter. I'm a season ticket holder. (11)*
>
> *Baking - I love baking one day I made a cake. I got a support worker with me. My mother's home help she looks after me. We go baking on the Thursday, we made a cake together it was really nice. (7)*
>
> *Everything if I can do it. Swimming, cycling, walking, shopping, cooking, housework. I help every day. Exercise. Get the sweeping brush like a partner. (28)*

Many people spoke about how they enjoyed socialising, seeing friends, boyfriends or girlfriends, visiting family, meeting and getting to know new people. Some people enjoyed spending time and interacting with animals, for example, their own or neighbours' pets, walking dogs.

Participants spoke about enjoying going on holiday and day trips; these were often organised by support providers or groups of or for people with learning disabilities.

> *We're planning a day out to [city] in September for people who live here and staff. It's £10 for transport. You pay for meals separately. (20)*
>
> *Enjoyed Chester Zoo, going to cinema, trips out with [provider friendship group]. (36)*
>
> *Support: "[She] goes on supported holidays and she just LOVES them. Don't you? And you try to go at least twice a year, don't you?"*
> *Participant: "Yeh."*
> *Buddy: "So where've you been?"*
> *Support: "[Names places in Britain], you go all over don't you?"*
> *Participant: "Yeh."*
> *Buddy: "So how, how do you go there, is it like a coach or is it - ?"*
> *Participant: "No, uh –"*
> *Support: "They come and pick you up from your house, it's all supported." (60)*

Some people had paid and unpaid work, for example in charity shops, supermarkets or at self-advocacy groups. This was another potential source of social contact.

Been making and selling tapestry and things at the market with support worker and one week a lady brought one for £10. (31)

Participant: I stack shelves, tins of food on shelves at [supermarket]…. Get a staff discount. I work for them. Discount. I work there all the time now. I been there too long me. A working badge. I work Fridays.
Buddy: What are the people like you work with?
Participant: They're alright. They talk together. I get my own dinner break in the staff room. (5)

Participant: But I work. At [the] market. I meet everybody there.
Buddy: What's the market like? Is it a good market?
Participant: Yeah.
Buddy: How did you get your job at the market?
Participant: I don't know. I know everybody there. I know [name], my boss I used to work with. (25)

I enjoy being on the committee. Working in the kitchen. Making cups of tea. Hoovering the floor. Being on reception. (34)

However, it could be difficult to find work and there were examples of barriers to people working, including health and discrimination.

Participant: Oh yes, I've just got myself a little job, it's only for an hour a day for four days, cleaning…..
Support: Can I just say [she's] worked very hard to get this job. And you've been for a lot of interviews haven't you so far? (59)

I used to do volunteering but I don't do it anymore with my health getting worse. Working with disabled people with a disability. And I passed my NVQ level 1. I used to work with [person's name] trying to get her active…..I used to be a volunteer, well like a member of staff, which I loved. Which I do at [the self-advocacy group], helping out there with people with a learning disability, even though I've got an illness. Well I can't work in any shops because they won't have me because of my walker. I've tried working in shops and things like that but there's no chance. I've worked in a library as a volunteer and had to give it up. (8)

Religion

Churches, religion and spirituality were important in some people's lives. Thirty-two participants described their religion as Christian. People spoke about how their church provided friendships, social contact and activities such as coffee mornings, luncheon clubs, arts and crafts and bible study. Some people did voluntary work through the church, for example at the church café. The church could play an important role throughout someone's life. However, some people lost contact with their church when they moved home or after their parents died and clearly missed this contact.

Living near your church (makes somewhere a good place to live)…..People at church talk to him. (55)

On Sunday I chill out and go to church (28)

[When I was younger] I used to go in the woods and have a few cigs. Parish priest copped me, not gone to church since my mum died…. It's hard. (15)

[It's hard to see] my old school friends and old church friends. I can't go to [where I used to live]. I would go back to church. Church helps me feel better (15)

Religion and spiritual beliefs could help people to remember loved ones and cope with growing older and one's own mortality. One person described their religion as 'reincarnation', and when asked how they felt about growing older, talked about a belief in a first and second life.

I should go to church to say a prayer for mum and dad (34)

Barriers and facilitators to taking part in activities.

We asked participants what or who helped or stopped them from doing activities that they enjoy or would like to try.

Support

Some people responded, often with pride, that they did things themselves, however, often people needed support to take part in social activities. Family members often supported them to do things; frequently this was parents or siblings. Family members growing older or dying could mean that people stopped doing things.

My parents are too old to do things with. (44)

Paid carers, personal assistants and staff also helped participants to do things; this could be supporting someone to plan, find out where places are and travel to them, and help with mobility. People could become more reliant on paid support as they grew older. However, people often shared support staff with other housemates, and availability of support could be a barrier to taking part in social activities.

Depends what staff are on (what we do on a Sunday) (20)

[Name of the] centre down the road has an art class on [day of the week]. You can go for coffee. It's not cheap. I've not been for 3 weeks because carer not here. (20)

Participant: "And I love going shopping."
Buddy: "Do you, so do you go out a lot?"
Participant: "If they've got the staff, yeh. Like this morning I should have gone weightwatchers, but we missed it."
Buddy: "So why did you miss it, because you didn't have the staff?"
Participant: "(There was only) [staff name] in, and [he] can't take me to - he had to take [my housemate somewhere] so we had to wait till 10 o'clock when [the other staff member] come in, then it means I have to miss my class." (2)

Some activities had stopped because of cuts to services and community groups in the time of austerity. In many areas, day services have closed or people have had

the number of days or hours they can spend at day services cut. Often, people did not get the opportunity or support to continue activities that they previously enjoyed in other settings.

> *"I miss my drama. My teacher been stopped it. At college. Stopped by the council. Because about money." (26)*

Age, health and mobility

Often, participants felt that their age, deteriorating health and mobility prevented them from doing things. Many people spoke of having falls and had a fear of falling; this could deter them from going out.

> *I have broken both hips. I need my stick and find it harder to get around. (35)*

> *Going to places I used to can be too much now I am older. (52)*

> *Learning Disability. Walking is difficult. Use my walker. I get out of breath so have to take my time. Eye sight and down syndrome…….[I would like to do] swimming, rock climbing, cycling, gym. I can't do these because of my disability. (8)*

> *Sometimes it's hard, I'm frightened of falling. Had the fall the other week and no one stopped to help. Sometimes a backwards fall. (21)*

Some people talked about and missed the fun they had when younger doing things that society considers inappropriate for adults or older people, or unhealthy.

> *"I used to like going on the park….I used to like going, but as you get older, you think, no, I'm giving up on the parks, too old for that now. So, I never go on the parks…. I mean if it's a nice day like this I'd go and sit in the park and just sit on the bench for a couple of hours , yeh… under the age of 11 is not allowed on the swings, so I couldn't go…you can make a flask of tea, some sandwiches, go and sit in park and have them." (48)*

> *Used to play games like hide and seek. I was a good kid at school. Caused mayhem, likes to joke. Stopped going to the chippy. (22)*

Cognitive differences

People with learning disabilities may have difficulties with memory, spatial awareness, learning and understanding. This can lead to problems with organisational skills, reading and counting, which can have practical implications when travelling or taking part in social activities.

> *I can't get across main roads. I can't manage 3 ways. I'm not good at directions. I can't get the train on my own. I can get the bus and walk on my own. (12)*

People may also find it hard to understand, learn and remember neuro-typical social rules and skills.

4. Growing older: feelings, experiences and beliefs

Negative aspects of growing older

The majority of people we spoke with viewed growing older negatively. Growing older was linked with negative emotions such as sadness, fear, anger and worry, and as something 'horrible' that they did not want to happen.

> *'Young is best.' (33)*
>
> *I don't want to grow old. I don't like it at all. Aches and pains. Fell and hurt my knee last year. (12)*
>
> *Buddy: "So how do people feel about growing older?"*
> *Participant A: "I don't like it"*
> *Others: 'not me!' 'I don't like it (laughing)*
> *Buddy: "You don't like it, lots of people don't like it, why don't you like it?"*
> *Participant B: "I don't know, cos I feel in myself I can do things, but I know I can't – "*
> *Participant C: "I feel more vulnerable –"*
> *Participant B:"I want to do things that I can't do."*
> *Buddy: "Have you got any examples?"*
> *Participant C: "a target, a target, cos I'm"*
> *Participant B: "Walking better, being healthier, that's what I'd like. Be able to join in with my grandchildren and my children and go places. Sometimes I say I can't go, so I'll stay here, you go and enjoy yourself." (58, 59, 61 – focus group)*

Generally, growing older was experienced as a time of loss. Some people felt that growing older would prevent them doing things that they enjoy. Deaths of people that they were close to, particularly parents, clearly had a great impact on people, emotionally and practically. Some people spoke about ways of remembering their people after they died, for example, by visiting their graves, and this was very important to them.

> *Participant: And I lost my mam as well. I can't eat. I'm having no breakfast at all in the morning. And I can't sleep during the night. Early about 4 o'clock, 5 o'clock, 6 o'clock. I can't sleep.*
> *Research buddy: Have you talked to anyone? A doctor or anyone?*
> *Participant: Not really. And I hear noises in my ear and I see twinkling stars and that scares me. I think I've got my mind on my mam and I want my mam back. And when I go on holiday I want to come home from holiday I want to tell my mam I had a good time and she's not there. (7)*
>
> *I used to go out shopping with my mum, I used to go on holidays with my mum and my dad and my stepdad until my mum died. And then when my mum died it all changed suddenly. (29)*

..and I just can't get on with [my new housemate]. Muttering Because I've lost my friend, he can't replace my friend. And I'll never get over it. I've missed him that much. So I'm going to see [the manager] after, see if she'll take me to see [my friend]. I won't rest until I see him again. I know I can't see him in person, but I can try and talk to him. (2)

However, people might not feel supported or allowed to grieve, talk about and remember their parents.

Co-researcher: "Do you ever feel lonely or have you ever felt lonely in the past?"
Participant: "Yeh." Pause.
Buddy: "Are you OK to tell us a bit about that?"
Participant: "Well it was ever since my dad died basically… Cos my dad was my best friend."
Buddy: "Yeh. Is there anyone you can talk to about losing your dad? Do you talk to people here about that?"
Participant: "At times yeh. I have actually seen a psychiatrist about it, but for me they go - they go on and on and on and on about the same bloody thing every time I go, instead of going on to different questions." (54)

Depressed. Feel like suicide. Had argument with carer because I wanted to cancel their shift to visit mum's grave. Carer said to talk to a counsellor. Hard to talk to someone you don't know. (4)

Often people had lived with their parents for all, or most of their lives, so when parents died this often led to loss of home, at a time that is already distressing.

8 years in [my current home]. Born in the area. Lived with parents until was 50. When mum died I moved to current housing. (20)

Health and mobility could decline and there were physical changes, such as hair going grey or getting thinner. One woman talked about the menopause, and some people expressed concerns about their own mortality and death.

Participant: "About growing old? Yeh, well your body changes doesn't it, cos you get, you're getting old every day, but you don't know what, you don't know what's going to happen to you inside, and you don't know what's going to happen to you when you when you die. Pause. Whether you're going to be the same, or whether you're going to .... [unclear] up as an old lady."
Buddy: "So the main thing that bothers you is, is knowing what's going to happen to you?"
Participant: "Yeh. Yeh. Pause. Because I'm on my own and in my house."
Buddy: "So not knowing what's going to happen"
Participant: "happen to me."
Buddy: "And things like body changing?"
Participant: "Yeh. And having the hot sweats and other things wrong with me." (29)

Co-researcher: "How do you feel about growing older?"
Participant: "Nervous. I don't like growing old."
Buddy: "Why do you not like growing old? What worries you?"

Participant: "Uhm, like, uhm, as you get older your legs starts going, slight pause your legs go. Or it could be your heart, anything like that. You know, and then snap, you're gone." (48)

For many people, this was a time of uncertainty about the impact of ageing and the future.

"How do I feel about growing older – I don't want to. I want to stay as I am, independent, I don't want to be old and I don't want anything to happen to me. If I'm like – if I'm I like that I would get – I would want some help, slight pause, but I don't want to be put into a nursing home or a care home." (29)

This uncertainty and lack of clarity about the future suggests that many people did not have the opportunity to talk to people about physical changes associated with growing older, or their feelings and concerns about growing older. It also indicates a lack of future planning and discussions about people's preferences about their future living arrangements; for example, after parents die or can no longer support them, or should the person's own health and mobility deteriorate.

I've wanted to move from day 1. It wasn't my choice. It really hits you when your family die. (4)

Positive aspects of growing older

Some people felt that growing older was an inevitable part of life, that 'we all grow old', it is 'just one of those things', and that age was 'just a number'. A few people commented that they still felt the same, that they were 'happy' or 'excited' about growing older, and that this was something 'good'. Many people continued to lead busy, active lives and see a range of people.

"Well [growing older] doesn't bother me. No, growing older doesn't bother me. I mean you grow older every day to be honest with you. That's the only thing that ever goes up and never comes down. It's your age." (54)

I'd rather stay as I am because I like to do things. I like music, I like to stay fit. I exercise a lot. I'm always happy. It makes me happy putting music on at the wrong speed. I'm a good walker. I do marathons to raise money. (9)

There were positive aspects to growing older. People could gain rewarding new roles within their family, such as becoming an uncle or aunty. People were clearly continuing to make a contribution. Some people talked about retirement; however, as discussed in the section about social activities, many people continued to do paid or voluntary work.

61 now. Have to cope with it. I'm retiring [from the self-advocacy group] soon. (17)

It's where I'm retiring to. I'm happy. It's nice. Relaxing. I go places. I lived in a flat on my own before moving here. It's better than where I used to live. (22)

Participant: I'm always cooking, I love cooking. I do voluntary cooking at [place]

Buddy: Oh right., so how often?
Participant: Well I help out, just Friday mornings.
Buddy: It sounds good, so do you go and do it as part of a group?
Participant: Yeh, there's a few of us. And we do it and we serve it, to people, you know, they can put donations in or it's free, you know, if they haven't much money they can just come in and have something to eat. (59)

Participants also talked about tasks they did to help at home, and providing practical support for family, neighbours, friends and the wider community.

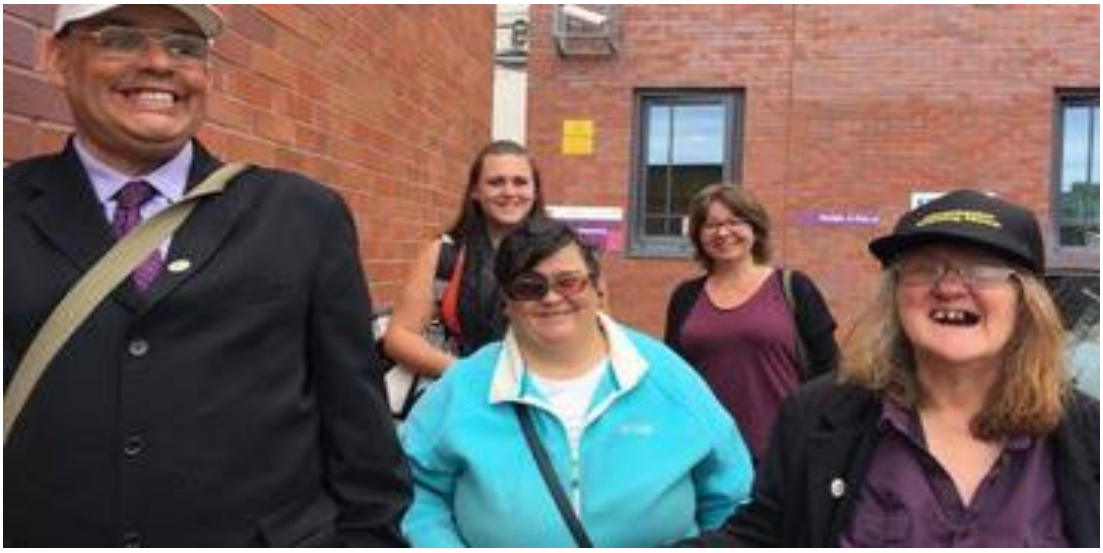
I do the bins. Tapes. Mum's shredding in the computing room. (19)

I do shopping for somebody who lives in the block who can't go out. She's very frail. She can go out but she needs support. I do a bit of shopping for her. (62)

My mum when she was alive, used to take her shopping and that. (15)

Discussion and recommendations

Our research aimed to find ways to reduce social isolation amongst older people with learning disabilities and help them to connect with local communities and wider society. There are many commonalities between what our participants told us and issues raised by older people without learning disabilities. Our themes fit well with the six aspects to age friendly places identified by *Ambition for Ageing*: community integration and belonging; opportunities for meeting and participation; accessibility, transport and facilities; community resources and spaces; feelings of safety; and information and communication (Thorley, 2018). Inequalities, discrimination and hate crime were also important, in common with older people with enduring mental health issues and some asylum seekers (Haslam, 2019; Nkurunziza, Syed, & Shama, 2019).



Inequality and discrimination

However, there are many differences between the experiences of our participants and many other older people. It was clear from people's stories that many of our participants had experienced a lifetime of negative events such as institutionalisation, stigma, discrimination and hate crime. These could impact on sense of belonging, confidence and self-esteem. Linked with this is that people are often at social and economic disadvantage; in common with most people with learning disabilities, many of our sample did not have long-term paid employment but had been dependent on benefits for most or all of their lives. This could make it harder to afford to go out, either to take part in social activities or to pay for transport to get to social activities safely. As they grow older, people with learning disabilities may face multiple discrimination in relation to their age as well as their disability and other factors (e.g. ethnicity, gender, sexuality).

These experiences of discrimination, segregation and low economic status may make people with learning disabilities more vulnerable to the negative impacts of growing older through the potential long-term impact on self-esteem and confidence. However, such experiences may make them more resilient and able to cope with the challenges of older age. Older people with learning disabilities may have developed ways of managing or coping with discrimination and hate crime and be linked into self-advocacy groups that support them to speak up for their rights. They may be accustomed to a low income, they might not miss relationships with work colleagues, may have built alternative relationships and activities, and created structure within their days and weeks.

Hate crime and the behaviour of children and young people clearly had a great impact on many of our participants' lives and affected whether they felt safe to go out. Some of our team were reluctant to travel when young people were using public transport. Hate crime is a common experience amongst people with learning disabilities (Strnadová et al., 2018) and there have been a number of campaigns, including a recent one on Manchester Metrolink (Greater Manchester Combined Authority, 2020). Changing public perceptions and behaviours towards people with learning disabilities may be long term but is vitally important to improve their lives and sense of belonging.

People with learning disabilities experience more health inequalities than the rest of the population and are likely to experience long-term health problems and multi morbidity at a younger age (Rickard & Donkin, 2018). Physical health or mobility often declines further with age. Many of our participants talked about the impact of health, mobility and fear of falling on whether they went out to socialise or take part in activities. They need support throughout their lives to live healthy lifestyles to remain healthy longer, and health providers need to be accessible and proactive in ensuring that health needs are met.

Our recommendations

- We need to find ways of changing negative public perceptions and behaviours towards people with learning disabilities.
- Health services need to ensure that they are accessible to people with learning disabilities.
- Services need to make sure that older people with learning disabilities know about and are getting health checks.
- People with learning disabilities can join their local Healthwatch to help improve health services in their area.
- People should get free prescriptions and dental care at a younger age if they need them and are on benefits. Some people do not get these. They need to be able to get benefits advice.

Social isolation and relationships

Social isolation might not be as important to older people with learning disabilities as loneliness. Many of our participants would not be considered socially isolated because of the number and frequency of their social contacts. However, often they were, or had been, lonely. Many expressed a desire for deeper, meaningful relationships, and missed the relationship they had with their parents.

Another distinctive and clearly important experience for older people with learning disabilities is the impact of the death or ageing of their parents. They may have lived with their parents for their whole life and still be living at home when parents die, or become too frail to provide them with practical support any more. Their parents may have been an important advocate and source of emotional and social support. Parents can be an important initiator and support of social activities (Mihaila, Handen, Christian, & Hartley). Moving out of the family home and living alone or with peers, may be a major transition that other older people have been through at a much younger age. This is a significant life change at a time when they are likely to be grieving and it is important that they receive long-term emotional support as well as support with practical aspects of life and personal care. Future planning with families is vital so that people can think about where they will live and the support they will need after they move out from the family home (Lee & Burke, 2020).

Our research shows that older people with learning disabilities can have busy, active social lives and contact with many people, including people in their local community. Our participants were involved in, or interested in, similar activities to those that many people enjoy whether or not they have learning disabilities and whatever the age. However, often their social lives take part in segregated groups and activities designed specifically for people with learning disabilities. These groups and activities may be important in their lives and can play a vital role in ensuring that people do not become socially isolated and feel welcome and valued. Such groups may know how to make their activities accessible and relevant to older people with learning disabilities. Self-advocacy groups play an important role in ensuring that people have a sense of belonging and awareness-raising about rights (Harrison, 2019). People may feel part of a learning disability community, even if they do not feel part of their local community, or communities of older or non-disabled people.

However, our findings show that life events could also lead to loss of existing contacts, for example, institutionalisation, death or difficult family relationships. Often, people are not supported to remain in contact with family and friends, particularly after transitions such as leaving school, leaving institutional care and moving house. Our research confirms that older people with learning disabilities are less likely to be in a long-term intimate relationship than other older people. Participants talked about difficulties meeting people and maintaining social relationships, such as arranging to meet people, getting to know people, keeping in touch.

People with learning disabilities may be less likely to meet new people, as often the membership of self-advocacy and community groups is relatively static. Groups and

activities are frequently organised through support providers or groups for people with learning disabilities and families and may not be open to people supported by other providers or living in a different geographical area. The funding of self-advocacy groups, community groups and activities has been under threat during cuts due to austerity; as has funding for support.

Our recommendations

- Broaden the membership of existing groups and activities to increase opportunities to meet new people
- More funding for self-advocacy groups and community organisations
- Information about social prescribing and community connectors for people with learning disabilities, their organisations and support providers
- Information, training and communication tools and strategies to help people with learning disabilities to understand rules and etiquettes surrounding social relationships (e.g. conversation starters).
- Matching people with learning disabilities with non-learning disabled people with similar interests, for example, through existing Good Neighbours and befriending schemes.
- Make sure that people's social needs are included in care plans and individual budgets and that support workers are clear that their role includes supporting people to develop relationships and access local communities.
- Information for older people with learning disabilities, families and support workers about social opportunities available locally and across Greater Manchester (e.g. Small Sparks web-site); often information is available only at a local authority area or online.
- Initiatives supporting people to develop relationships and take part in social activities (e.g. Supported Loving Network, friendship and dating agencies such as Meet 'n' Match, friendship groups, gig buddies) must ensure they are promoted to and accessible for older people (e.g. quiet venues for people with impaired hearing, a range of activities for different interests, life experiences and personalities).

Older people's services and networks

Currently statutory and community services for older people and people with learning disabilities appear to operate completely separately in different 'service worlds'. Developing links between existing initiatives for reducing older people at risk of social isolation (e.g. Red Cross Assisted Discharge Service, Community Paramedics, befriending services) and learning disability services (e.g. community teams, acute liaison nurses) may help to identify and support isolated people with learning disabilities. Some areas have involved fire services to help them to identify isolated people (e.g. https://timetoshineleeds.org/blog/safe-and-well-with-west-yorkshire-fire-and-rescue-service).

There were few examples of participants accessing groups and activities designed for older people, although some people mentioned going to activities or having social contacts through a church. This may be because we accessed most of our participants through self-advocacy groups and health and social care providers. Alternatively, it may show that general provision for older people is not usually inclusive of people with learning disabilities, people may be unaware of their existence, or may not meet eligibility criteria. This also reflects findings from other projects funded by *Ambition for Ageing* that small dispersed communities of identity or experience are often not well served in communities in Greater Manchester (Nkurunziza et al., 2019; Simelionyte, 2020).

There seemed to be a genuine commitment to involving older people with learning disabilities within the wider *Ambition for Ageing* programme and older people networks in Greater Manchester. However, we observed that many of the events and networks for older people were not accessible to our team members with learning disabilities, most of whom are experienced attenders of meetings and events. Examples include use of jargon, inaccessible information, long formal meeting formats, a move to digital rather than paper resources, length and timing, and a focus on information-giving. Guidelines already exist about making meetings and events accessible for people with learning disabilities which would be useful for older people services, generic services, social and leisure providers and community groups (for example, (Disabled People's Network Steering Group., nd; Manchester People First, nd-a, nd-b).

Our recommendations

- Older people's networks, groups and services need to be accessible to older people with learning disabilities. Ideas of how to do this include:
    - People with learning disabilities delivering training to these venues
    - Sharing information about how to improve accessibility
    - People with learning disabilities acting as quality checkers or 'mystery shoppers'.

Growing Older

Our research shows that the majority of our participants had a negative attitude towards growing older. This is comparable with the views expressed by the media, older people themselves, and the general population, which often follow a narrative of blame and societal burden. There is a clear need to challenge negative stereotypes and promote positive images of ageing. Rather than viewing older people as a burden and separate from society, ageing should be recognised as part of the life-course and as applying to all. The Age Proud movement has drawn attention to positive aspects of ageing, such as time to focus on interests and try new experiences, more time to spend with family and friends, financial security, living in the moment, increased confidence, understanding, and resilience (Jones, 2019).

It is important that older people with learning disabilities are included in the Age Proud movement. Our research shows that older people with learning disabilities have skills, knowledge, lived experience, a sense of history and identity and make a valuable contribution to society. They need opportunities to reflect upon their achievements, and to share their knowledge, skills and experiences with other older people and with younger people through intergenerational projects.

People with learning disabilities, families and support workers clearly need more information, support and opportunities to talk about growing older. There is information about growing older for family and support workers, but little for people with learning disabilities and the focus within health and social care services tends to have been on end of life (Gray & Kim, 2020; Tuffrey-Wijne, 2020). However, there is less about ageing well and having a good life as you grow older. People with learning disabilities need to understand physical changes such as the menopause.

Our recommendations

- People with learning disabilities need more information and training about growing older.

- They need to hear about good things about growing older:

    - People still have lots of friends and go out.
    - Radio shows could tell people about growing older and how to have a good life.
    - The co-researchers can give examples about what is good from our lives.

- Our team members could become GM GOLD champions who talk to people and services and do training about growing older.

Accessibility, transport and feeling safe

Ensuring that the physical environment is accessible also plays an important role in the social inclusion of older people with learning disabilities. Accessible housing options, kerbs and physical access to buildings are needed for people with mobility issues. Signage and ways of making the physical environment easier to navigate are needed to help people find their way. Better lighting will help with mobility and feeling safe.

Whilst transport is a common concern for older people, people with learning disabilities may need additional adjustments; for example, accessible timetables and verbal stop announcements. They may need support to get to places, particularly for the first time. Participants had a range of suggestions and strategies for improving safety, such as personal alarms, emergency numbers on telephones, and travelling in a group.

Places in the community need to be welcoming and accessible to older people with learning disabilities (Mooney et al., 2019). Staff at local sports and leisure venues need to be more aware of the different people in their community who might need support to use the facilities. They need to understand that not all people with a learning disability or autism may easily be recognised as people needing extra support. This could be achieved by providing training delivered by people with a learning disability for staff and volunteers.

Our recommendations

- Places, groups and activities within communities need to be inclusive of older people with learning disabilities. This goes beyond physical accessibility; accessible information and attitudes are also important.

- Many older people with learning disabilities need support to travel and use public transport. Ideas are:
    - Travel training
    - More help at bus stations and tram stops
    - Speaking timetables
    - Stop announcements on buses as well as trams
    - Individual budgets should include money for support to travel. This should be built into care and support plans.
    - How to use apps (e.g. citymapper)
    - Training for taxi drivers
    - Taxi concessions for older people from the council or schemes to make taxi travel cheaper.Reduced taxi fares for people with a travel pass who cannot use public transport.
    - Improved ring and ride services; they can be hard to book. There is often a limit on how far they will take people. They are often late or early.

- Our ideas to help older people with learning disabilities to feel safe are

- More hate crime campaigns
- More police who can help, especially in areas where there is the most trouble.
- More security cameras (CCTV)
- Well-lit neighbourhoods
- Knowing more about personal safety / how to keep safe training
- More places where people can go if they feel unsafe.

Methodological issues

The GM GOLD project and the research findings are an important contribution to making people with learning disabilities more visible, and ensuring that people with learning disabilities, their life experiences and perspectives are included in research. Many participants were very open about their feelings and experiences, demonstrating that the research created safe spaces for people to talk, and perhaps that participants were more willing to be open about their feelings when being interviewed by other people with learning disabilities.

There are a number of limitations to our research. Although we tried hard to reach isolated older people with learning disabilities, we struggled to find people who had no social contacts. This was a common struggle mentioned by learning disability and older people services during the project; if people are isolated they will often be 'hidden' and hard to identify. Despite extensive efforts to try to find people through a variety of ways, most of our participants were recruited through self-advocacy groups and support providers and therefore, would have some form of regular social contact and not necessarily be defined as socially isolated.

Our sample may not reflect the diversity of older people with learning disabilities across Greater Manchester. We had a wide age-range and a mix of sexual identities. We did not have equal numbers of men and women, but it is usual that more men than women are identified as having learning disabilities internationally (Hatton, 2020). Whilst Greater Manchester is a culturally diverse region, the majority of our sample identified as White British and our research did not include anyone from an Asian background, despite there being a higher prevalence of people with learning disabilities in these communities (Mir, Nocon, Ahmad, & Jones, 2001). Therefore, we did not capture the experiences of people from a range of ethnic and cultural backgrounds. Our difficulty identifying people from different cultures may be because specialist learning disability services are inaccessible to people from minority ethnic communities (Caton, Starling, Burton, Azmi, & Chapman, 2007; Mir et al., 2001). We did approach support groups for families from South Asian backgrounds and they offered to share information about the project; however, they knew few families with older members who would have been eligible to take part.

Dementia is more common amongst older people with learning disabilities, and people with Down Syndrome are more likely to develop dementia at a younger age (Chapman, Lacey, & Jervis, 2018). However, this did not arise as a major issue in our project. We tried to include people who were known to have a diagnosis of

dementia but it was usually considered to be an inappropriate time for them to take part, either due to declines related to dementia or life events. One participant did have a diagnosis of dementia but was not aware of this.

We wanted to include people with a range of communication needs and with severe and profound learning disabilities. We considered different ways of including people with a range of severity of learning disability and had a process in place so that we could include people who were not considered to have capacity to consent but did not need to use this during the fieldwork. Most of our participants were verbal and would probably be considered as having mild to moderate learning disabilities. Sometimes it was difficult to understand what people were saying if we did not know them well. Participants often assumed we knew their local area or people that they were talking about so it was sometimes hard to locate their information in the context of place or relationships.

Our team designed a structured interview guide to support interviewers to remember what questions to ask and to enable buddies to record responses. Sometimes, however, the co-researchers seemed to feel under pressure to read every question correctly and read out the response options, rather than waiting for someone to respond in their own words. This also guided what topics were talked about during interviews, so other important issues may have been missed. A more open, flexible approach to interviews and questioning might have provided more detailed qualitative information. A life story approach would have enabled more insight into long-term influences on relationships and sense of belonging.

It was important that we offered both focus groups and interviews. The co-researchers felt that many of their peers would feel more comfortable in a group setting than an individual interview. Some people took part in both and shared information about their lives in the focus groups that they did not in interviews (and *vice versa*). We also learnt many important things about the lives of older people with learning disabilities from each other during the research. Co-researchers shared information that did not arise in their interviews but which gave important, detailed insight into why older people with learning disabilities may become isolated. Spending more time to build relationships with fewer participants would have enabled us to develop trust and gain more in-depth information about their lives and feelings.

Our ideas for future research

We think it is important that research is co-produced with people with learning disabilities. The co-researchers have many ideas for more research; for example, we would like to find out more about social isolation and older people with learning disabilities not represented in this research (e.g. people from different cultural backgrounds) and we would like to find out more about health. However, we would need continued funding, training and support to do this.

Our promotional campaign

We have been telling people about how important it is to improve the lives of older people with learning disabilities throughout our project. We have been to Ambition for Ageing, Equality Board, Age-Friendly Manchester and Greater Manchester Older People Network workshops and events and spoke about the project on a radio show. We have contributed to the training of nursing, health and social care undergraduate students at Manchester Metropolitan and the University of Manchester. We have presented at conferences about the lives of people with learning disabilities and developed a workshop on growing older for self-advocates at their regional conference, 2020 Vision. We have started to share #AgeProud photographs of older people with learning disabilities so that they are included in the wider Age Proud campaign.

We want our campaign to promote better lives for older people with learning disabilities and awareness-raising to continue beyond the end of the project's funding on 31st March 2020. We hope that the co-researchers will act as GM GOLD champions (or ambassadors), telling people with learning disabilities, families, service providers and commissioners what we have found out and what needs to happen. We have produced an easy-read report and presentation for them to use to do this. The co-researchers may need further support and training to plan and do this beyond the project end date.

Unfortunately, the impact of the coronavirus Covid-19 outbreak in February and March 2020 has delayed our celebration event and the production of a film to help to share our findings. This has prevented us attending meetings and taking part in other events (e.g. Equalities Board and GM Older People's network event; taking part in a human library at the Talking About My Generation celebration event). The outbreak has highlighted how important it is to reduce social isolation and ensure that older people with learning disabilities are connected with local services and communities. We hope to continue our promotional activities once the situation improves.

Daniel and Delwyn presented at Making Research Count, Uni of Salford, March 2019

Conclusions

Our research shows that later life transitions for people with learning disabilities are particularly disruptive, and that they are at particular risk of social isolation and loneliness, and therefore, the potential impacts on independence and wellbeing. People with learning disabilities have the same rights to relationships and to participate in the cultural life of the community as the rest of society. If society, neighbourhoods and communities do not become more inclusive of people with learning disabilities, in addition to the legal, moral and ethical implications, this is likely to result in additional demand for public services.

In 2018/19, 297,174 people of all ages were registered as having learning disabilities with their GP (NHS Digital, 2019). A total of 150,620 adults with learning disabilities were receiving some form of long-term social care; 133,575 of whom were aged 18-64 and 17,045 were aged 65+. The greatest growth in social care demand is from working age adults, 45% of whom have learning disabilities, compared to just 3% of over 65s (Bottery, Ward, & Fenney, 2019). Without significant change, as people with learning disabilities grow older demand for health and social care will increase. It is not solely the responsibility of health and social care providers to reduce the impact of social isolation on independence, health and wellbeing; community organisations, shops, sports and leisure facilities, and the general public have an important part to play.

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